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SUMMARY REPORT
"Current Healthcare Informatics Standards Activities of Federal Agencies"

A Meeting Sponsored by the
Agency for Health Care Policy and Research (AHCPR)

Hyatt Regency Hotel, Bethesda Maryland
January 12, 1999

Introduction

In September 1996 the Agency for Health Care Policy and Research (AHCPR) produced a compendium covering health informatics-related initiatives in the federal government: "Healthcare Informatics Standards Activities of Selected Federal Agencies." That document contained contributions from a wide range of federal agencies and offices.

Since the publication of that document, AHCPR staff have been in periodic contact with the designated contacts of the contributor agencies. During 1997 and 1998 the agency contacts were requested, on an as needed basis, to update their contributions to the compendium. In addition, the contributors were requested to provide information on any agency initiatives related to the implementation of the Health Insurance Portability and Accountability Act (HIPAA) of 1996. These periodic contacts resulted in the production of several draft revisions of the compendium over the course of 1997-1999.

During this same timeframe AHCPR staff continued to make efforts to establish contact points at agencies that had not contributed to the 1996 document. These contacts resulted in the submission of compendium contributions from several agencies that did not have contributions in the 1996 document. These agencies included the Consumer Product Safety Commission, the Bureau of Labor Statistics, and the Department of Energy. Contributions from these agencies were included in the 1997 and 1998 draft documents.

AHCPR plans to publish the second edition of the federal activities compendium in June 1999. In the fall of 1998 all of the compendium contributors were contacted and asked to rewrite and update their contributions. At the same time these contacts were being made AHCPR invited the agency contacts to a contributors meeting. That meeting was held at the Hyatt Regency Hotel in Bethesda, Maryland, on January 12, 1999.

This meeting had several objectives. One was to allow the agency representatives to obtain a more detailed understanding of current standards activities than they could obtain from the overviews provided in the compendium. Second, the meeting provided the representatives with an opportunity to identify the key near-term informatics challenges that need to be addressed by federal agencies.

The remaining sections of this report briefly describe the meeting's discussions and list the near-term challenges identified by the meeting participants.

Meeting Summary

The January 12 meeting opened with three presentations providing overviews of the current status of data standards development, both nationally and internationally. The first presentation was by J. Michael Fitzmaurice, Ph.D. of AHCPR. Dr. Fitzmaurice is the Senior Science Advisor for Information Technology within the immediate office of the AHCPR Administrator.

In his opening remarks Dr. Fitzmaurice discussed the context for federal healthcare data standards development. He noted that in this area Federal agencies operate under several mandates including an OMB directive stipulating that Federal agencies are to use private sector standards where feasible. In addition, Vice-President Gore has directed Secretary Shalala to improve Federal agency coordination for health data standards. Federal agencies working with healthcare data must also be eventually meet the requirements of the White House National Information Infrastructure Initiative as well as meet the implementation requirements of HIPAA. Dr. Fitzmaurice noted that in 1998 considerable progress had been made in establishing HIPAA standards. Four notices of proposed rule making (NPRMS) were published in 1998 including those for Claims and Codes, a National Provider Identifier (10), an Employer ID, and a Security standard. A standard for the Health Plan ID is to be published in 1999.

Dr. Fitzmaurice's remarks were followed with a presentation by Peter Waegemann, Executive Director of the Medical Records Institute. Mr. Waegemann also serves as the Chair of the ANSI Healthcare Informatics Standards Board (HISB) and as Chair of the US Technical Advisory Group to the IS0 TC 215 on Health Informatics. Mr. Waegemann's presentation provided an historical overview of the development of healthcare data standards as well as a delineation of the major challenges currently faced by healthcare information professionals. Mr. Waegemann pointed out that there had been three distinct phases in the development of healthcare data standards. There was a pre-1988 generation of standards developed in response to the large-scale introduction of electronic record keeping systems. A second phase (1988-l 998) of standards development reacted to the widespread use of personal computers in maintaining records. A third phase, just now beginning, will have to develop standards that that can meet the requirements of a web-based healthcare communication system.

Mr. Waegemann identified 7 major trends in the latest phase of healthcare standards development, these being:

- A Need for and a Move Toward Interoperability
- A Need for Improving Clinical Specificity
- A Need for Defining Report Cards
- A Need for Ensuring Privacy, Confidentiality, and Data Security
- A Need for Enhancing Organizational Productivity, i.e. Decision Support Systems
- Making Initial Attempts at Accreditation
- Development of Documentation Standards

In addition to the technical complexity posed by these challenges, Mr. Waegemann also discussed the organizational and jurisdictional complexity of the standards development process. Internationally, at least 30 countries currently are engaged in standards development activities. Within the US standards development activities are fragmented among a large number of organizations and work groups, the most important being those currently being coordinated under the umbrella of the ANSI HISB committee. These organizations include the American Dental Association, the ASTM E3 1 subcommittees on Healthcare Informatics, the Health Industry Business Communication Council, Health Level 7, the Institute of Electrical and Electronic Engineers, the National Council for Prescription Drug Programs, and the Accredited Standards Committee on Insurance Interchange Standards (X 12N).

Mr. Waegemann concluded his remarks with a recommendation that federal agency representatives become much more active in ongoing standards development activities. He actively encouraged federal agency representation at the ANSI HISB and associated TAG meetings to be held in Washington DC from March 17 through March 19, 1999.

Mr. Waegemann's remarks were followed with a presentation by Claudia Tessier. Ms. Tessier is Executive Director of the American Association for Medical Transcription. In addition, Ms. Tessier serves as the Chair of the ASTM #3 1 Committee on Healthcare Informatics. Ms. Tessier's remarks focused on the use of one specific function, medical transcription, that could benefit from the development of data standards.

Ms. Tessier pointed out that transcription services currently cost federal agencies at least $3 billion annually. However, there exists no quality standard for transcription, and transcription professionals can employ a wide variety of formats. This lack of standardization almost certainly will be a major impediment to the maintenance of electronic healthcare data systems.

Ms. Tessier proposed that federal agencies support the establishment of standards for medical transcription. Such standards would cover practice and style, formats, quality of transcription, and the types of acceptable data capture techniques such as speech recognition. Development and implementation of such standards would greatly improve the uniformity and ease of transmission of healthcare data. In all likelihood, such standards would also produce measurable improvements in patient care.

Ms. Tessier stressed that this was an area where federal agencies could be the "driving" force in standards development. Adoption of a single set of transcription standards by federal agencies would almost inevitably lead to the adoption of the same or similar standards by the private sector. Substantial cost savings and improved patient care would be the likely result of the implementation of such standards.

These opening talks were followed by a series of 5- 10 minute presentations by representatives of contributing agencies sending spokespersons to the meeting. Those agencies making presentations at the meeting included:

- **The Agency for Health Care Policy and Research, Presenter Dr. Michael Fitzmaurice.** In his remarks Dr. Fitzmaurice presented a brief overview of the data collection activities of AHCPR, including the Medical Expenditure Panel Survey and the HIV Cost and Service Utilization Survey. Further, Dr. Fitzmaurice described AHCPR's support of ANSI's Healthcare Informatics Standard Board and of the U.S. Technical Advisory Group to IS0 Technical Committee 215, Health Informatics, to improve coordination and cooperation on health data standards development nationally and internationally. Dr. Fitzmaurice also discussed AHCPR's ongoing responsibility to develop data standards that meet the requirements stipulated in HIPAA and his role as co-lead staff to the Computer-based Patient Record Work Group of the National Committee on Vital and Health Statistics. This working group has the responsibility to draft a Congressionally mandated report on standards for patient record information and its electronic exchange.

- **Centers for Disease Control and Prevention & Agency for Toxic Substance and Disease Registry, Presenter Dr. Ronald Fichtner.** Dr. Fichtner explained CDC's strong interest in promoting data standards in order to enhance its surveillance and prevention programs. Recent CDC initiatives include development of the National Immunization Program (NIP) which includes standard query, response, and update messages for immunization records. In addition, the National Center for Chronic Disease Prevention and Health Promotion is attempting to develop a similar mechanism for cancer registries. Related to this initiative, in August 1998 a meeting was. held with CDC, the North American Association of Cancer Registries, and HL7 representatives, to explore the possibility of a standardized electronic exchange protocol,

- **The Centers for Disease Control & Prevention, National Center for Health Statistics, Presenter Marjorie Greenberg.** Ms. Greenberg provided an overview of NCHS' role as the World Health Organization (WHO) Collaborating Center for the Classification of Diseases for North America. In addition, Ms. Greenberg discussed the November 1998 HIPAA-related workshop sponsored by NCHS. This workshop was entitled "Implications of HIPAA's Administrative Simplification Provisions for Public Health and Health Services Research." This workshop resulted in a Workgroup for representing health and health services research data needs in the standards development process.

- **The Food and Drug Administration, Presenter Dr. Charles Fur-fine.** Dr. Furfine's remarks concentrated on FDA's interest and support for

international standards. These efforts include the FDA-developed Coding Symbols for a Thesaurus of Adverse Reaction Terms (COSTART). In addition, the FDA is active on the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH), and the Global Harmonization Task Force for medical devices.

- **The Health Care Financing Administration, Presenter Mr. Bob Mayes**. Mr. Mayes provided an overview of HCFA's need to obtain consistent data on such key issues as measures of beneficiary satisfaction, cost, and types of interventions. In addition, Mr. Mayes stressed the need for federal agencies to become more actively involved in the standards development process, both in the US and internationally.

- **The National Institutes of Health, National Library of Medicine, Presenter Ms. Betsy Humphreys.** Ms. Humphreys presented a synopsis of the most recent NLM efforts in standards development. Current activities in this area include having Ms. Humphreys serve as co-chair of the Codes and Classifications Implementation Team for HIPAA Administrative Simplification.

- **The Department of Defense, Presenter Mr. Marco Johnson.** Mr. Johnson provided an overview of the current DOD Data Standards Strategic Plan. This initiative will employ a "top-down" mission/goals approach to be based on preexisting customer-driven systems. A key aspect of the effort will be a community-wide Data Quality Action Team that will address all aspects of the data quality issue.

- **The Bureau of Labor Statistics, Presenter Mr. Guy Toscano.** Mr. Toscano provided an overview of the two healthcare data sets maintained by BLS, the Survey of Occupational Injuries and Illnesses, and the Census of Fatal Occupational Injuries. In addition, Mr. Toscano stressed BLS' ongoing need for standardized data that specifies the source and context of injuries and illnesses.

- **The Department of State, Presenter Ms. Jennifer Grise.** Ms. Grise explained DoS' need to maintain medical records on Foreign Service employees and dependents serving in over 250 locations worldwide. Ms. Grise also provided a description of the development two DoS database management systems, the Worldwide Health Resources Risks and Recommendations System, and the DoS Electronic Medical Record System.

- **The National Highway Traffic Safety Administration, Presenter Mr. Garry Criddle.** Mr. Criddle pointed out that while NHTSA does not have any regulatory authority, it does promote standards through its development of twelve National Standard Curricula for emergency medical services and emergency medical technicians. In addition, Mr. Criddle stressed NHTSA's

need for standardized medical data to accurately assess the impact of safety programs and devices.

- **The Department of Veterans Affairs, Presenter Mr. Greg Seppala.** In his presentation Mr. Seppala stressed VA's proactive role in promoting standards development throughout the VHA medical system. In addition, Mr. Seppela mentioned that VHA is providing funds to support an HL7 Government Projects Special Interest Group to expedite processing of proposals that benefit the Government Computer-based Patient Record (GCPR) initiative.

- **The Consumer Product Safety Commission, Presenter Ms. Robin Lingle.** Ms. Lingle provided brief overviews of the healthcare related data sets maintained by the CPSC. These include the National Injury Surveillance System, the CPSC Death Certificate Project, and the Injury and Potential Injury Incident data set. In addition, Ms. Lingle stressed the need of CPSC for medical data that reported the proximate cause and context of accidents and injuries.

- **The Social Security Administration, Presenters Mr. Derek Wang and Ms. Debbie Somers.** The SSA presenters provided overviews of the agency's collaborative efforts including its ongoing partnership with the VA. This project is an effort to establish a policy and framework that will allow State disability examiners online access to the automated patient records maintained by VA medical examiners. In addition, the presenters stressed the agency's ongoing interest in ensuring full implementation of healthcare data standards.

- **The Office of Personnel Management, Presenter Mr. Leroy Strickland.** Mr. Strickland pointed out that OPM has a major interest in healthcare data standards since OPM administers the Federal Employees Health Benefits Program (FEHBO). This program covers approximately 9 million Federal employees, retirees, and family members. In addition, OPM is routinely asked to supply government-wide data on the incidence of specific health problems and interventions.

Near-Term Challenges

After the conclusion of the agency presentations there was a group discussion in which the participants identified a number of near-term challenges. These challenges are all data standards issues or concerns that will have to be addressed by federal managers. Presented below is a list of the challenges identified by the meeting participants. The challenges are listed below in the order mentioned by participants in the group discussion. The order of the list does not imply any prioritization on the part of the participants.

The challenges identified by the participants included:

- **The Cost of (Agency) Participation in Standards Activities. The Business Case for a More Active Federal Role –** This issue reflected a concern that agencies were not devoting enough staff time and budget support (e.g., travel expenses to major meetings) to this issue. Some participants believed that federal managers should make a strong case that their agencies needed to be represented in ongoing standards developments activities.

- **Determining How Agencies will Chart Their Own Course for Establishing Standards –** A number of participants pointed out that there were not clear procedures within departments or agencies as to how standards would be developed. This procedural issue needs to be addressed by federal managers.

- **Determining How Agencies can Meet the Needs of Providers –** Some participants saw a federal role in supporting the development of standards that met the requirements of healthcare providers, both for public and private sector programs.

- **Projecting and Preparing for HIPAA Impacts –** The participants agreed that most federal agencies would not have a proactive role in developing the public sector response to HIPAA's requirements. However, there was agreement that each agency would have to anticipate HIPAA's impact on the public and private sector organizations with which they interact, and on their own health programs.

- **Enhancing Agency to Agency Coordination –** Participants agreed that the number of inter-agency initiatives (e.g., SSA and VA) needed to beexpanded, and that there was a need for enhanced interagency communication.

- **Increasing the Level of Priority Given to Standards Activities at the Agency Level –** The participants agreed that that senior agency managers need to be alerted to the probable impact of standards development and implementation.

- **Determining if There Should be Separate or Combined Federal Standards –** There was agreement that there needed to be some sort of determination if a "one size fits all" could be developed for federal agencies or if there needed to be standards developed for specific agency missions and functions.

- **Addressing the Lack of Focus of Standards Activities across Enterprises –** The participants agreed that there needed to be inter-agency initiatives that identified standards requirements and implementation issues across enterprise boundaries, e.g., Social Security and Medicare.

- **Development of a Comprehensive List of Current Federal Initiatives Related to Standards Development –** There was general agreement that there needed to be a communication resource that would allow federal managers to identify all standards-related initiatives and work groups.

- **Determining if Existing Groups (e.g., ANSI-HISB) can Facilitate the Federal Standards Development Process –** Participants expressed concern regarding the ability of existing standards-development bodies to successfully address the concerns of federal agencies.

- **Development of Strategies for Implementation, Particularly with Respect to HIPAA –** Participants saw a need for a federal initiative(s) that will address obstacles to implementation of standards and can monitor compliance.

- **Ensuring the Application of Appropriate Technology for Standards Implementation –** Participants agreed that successful implementation of standards would be heavily dependent on the compatibility of the standards with emerging database and electronic communication technologies.

- **Relating Federal Activities to the International Standards Development Process –** The participants agreed that federal agencies must remain cognizant of the international activities as well as increasing the federal presence in the international health data standards development process.

- **Establishing How Content Should be Developed for Standards –** There was agreement that federal agencies should establish agreed upon formal procedures for developing the content of specific standards.

- **Finding Ways to Leverage Resources Outside the Healthcare Industry –** Participants agreed that federal agencies should develop creative strategies for locating technologies that facilitate implementation of standards.

- **Determining How Individuals and Agencies will Have Access to Standards –** There was general agreement that federal agencies should develop easily accessible reference sources that provide explanations and definitions of health data standards. A health data set registry that contains answers to a common set of questions asked of health data sets would be a significant step forward.

- **Determining the Appropriate Government Role in the Maintenance of Standards –** The participants agreed that the federal government should establish procedures for the periodic review and updating of health data standards used in its programs and in the private sector.

- **Addressing Confidentiality Concerns –** The participants agreed that all data standards systems must include adequate mechanisms to ensure the confidentiality of patient data.

Contact Information

To gain additional information about this AHCPR initiative interested parties can contact either J. Michael Fitzmaurice, Ph.D., or Stanley Edinger, Ph.D., at AHCPR. Dr. Fitzmaurice can be reached at (301) 594-3938 while Dr. Edinger can be reached at (301) 594-l 598. Their respective email addresses are: mfitzmau@ahcpr.gov and Sedinger@ahcpr.gov.

HEALTHCARE INFORMATICS STANDARDS ACTIVITIES OF SELECTED FEDERAL AGENCIES

(A Compendium)

September 1999

Sponsored by:

Agency for Health Care Policy and Research

Introduction

The Agency for Health Care Policy Research and Research (AHCPR) is producing this report to compile health care informatics standards activities that have been voluntarily reported by selected federal agencies.

The AHCPR has undertaken this initiative to assist (1) the Secretary of Health and Human Services in making health data standards choices for administrative simplification (mandated under PL 104-l 91), (2) the Department of Health and Human Services (DHHS) Data Council's oversight of health data standards, and (3) the White House in meeting the goals of the Administration to promote the widespread use of the National Information Infrastructure (NII) in health care. The report also provides information to assist DHHS in responding to a request of Vice President Gore (March 1995) to improve the coordination of federal activities in health care data standards development.

As part of its work plan, the Data Council is undertaking this federal coordination through its Committee on Health Data Standards by documenting existing federal health data standards activities. This report complements a current review, also provided by AHCPR, of the activities of the major private sector standards development organizations: *Current Activities of Selected Health Care Informatics Standards Organizations (A Compilation), June 1998.*

The information presented in this report has been solicited from federal agencies that are among the most active in drafting and promulgating standards for health care data collection and reporting. Each of these organizations was contacted and asked to provide information about the following ten areas: (1) a contact person; (2) data related programs; (3) standards employed; (4) purpose of the standards; (5) subject areas covered; (6) standards activities; (7) data dictionaries; (8) publications and other disseminations; (9) participation in American National Standards Institute (ANSI)-accredited and other standards development organizations; and (10) Health Insurance Portability and Accountability Act (HIPAA 1996) related activities. This was followed-up with onsite interviews and agency opportunities to revise the information provided prior to publication of this document. This study does not include all federal agencies and all their health care standards activities.

The compendium project team has been in contact with a number of agencies that maintain databases containing health statistics and health-related data in addition to the ones submitting information for this edition of the compendium. These agencies include the Bureau of the Census, the Coast Guard, the Bureau of Prisons, Central Intelligence Agency (CIA), the Immigration and Naturalization Service, the Federal Emergency Management Administration (FEMA), the Environmental Protection Agency (EPA), the Occupational Safety and Health Administration (OSHA), and the National Park Service. AHCPR will set up procedures to allow these and other agencies to submit information after the publication of this report.

In the fall of 1998 all of the compendium contributors were contacted and asked to see if their contributions needed any final corrections or updates. At the same time these contacts were

being made AHCPR also invited the agency contacts to a contributors meeting. That meeting was held at the Hyatt Regency Hotel in Bethesda, Maryland, on January 12, 1999.

This meeting had several objectives. One was to allow the agency representatives to obtain a more detailed understanding of current standards activities than they could obtain from the overviews provided in the compendium. In addition, the meeting provided the representatives with an opportunity to identify the key near-term informatics challenges that need to be addressed by federal agencies. AHCPR has produced a report that summarizes the participant discussions at this meeting.

Both this report and the summary meeting report will be available on AHCPR's web page located at http://www.ahcpr.gov/data. The DHHS Data Council's web page is located at http://www.aspe.os.dhhs.gov/datacncl/index.htm. Information on DHHS administration simplification activities (associated with PL 104- 19 1) may be found at http://www.aspe.os.dhhs.gov/adminsimp. The general program activities of DHHS agencies can be found on the DHHS web page located at http://www.os.dhhs.gov. Information on the NII is available on the NII web page located at http://nii.nist.gov.

The collection and compilation of this information in this document was carried out by The Washington Consulting Group, Inc. (WCG), under the direction of J. Michael Fitzmaurice, Ph.D., and the management of Stanley E. Edinger, Ph.D. The diligent work of Cyrus Baghelai and Richard Hilton both of WCG is greatly appreciated. Suggestions for improvements or revisions are welcome and may be made to AHCPR by contacting:

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DATA-RELATED PROGRAMS:

AHCPR undertakes the Medical Expenditure Panel Survey which collects data on the specific services that Americans use, how frequently they use them, the cost of these services, and how they are paid, as well as data on the cost, scope, and breadth of private health insurance held by and available to the U.S. population. The Agency, under the Health Cost and Utilization Program (HCUP), maintains information on inpatient hospital stays, and the HIV Cost and Service Utilization Survey (HCSUS) collects, cost and utilization data about the services used by persons with HIV. For over 28 years, AHCPR has funded the development, application, and use of health information systems, including the MUMPS programming language and COSTAR (an early computerized ambulatory record system). AHCPR and the National Library of Medicine (NLM) are in partnership to support applications of the electronic medical record, for example, defining laboratory (e.g., LOINC – Logical Observations, Identifiers, Names, and Codes) and imaging standards, and developing and testing common medical terminology for the electronic patient record. AHCPR funds studies of specific applications of computerized clinical decision support systems for health providers as a member of the White House Computing, Information, and Communications Research and Development (CICR & D) program. AHCPR also participates in DHHS development of core data sets and in health services research activities on critical data issues such as health data standards and the confidentiality of personal health information.

STANDARDS EMPLOYED:

ICD-9-CM diagnosis codes and procedure codes and CPT-4 and HCPCS procedures codes for ambulatory procedures are used in AHCPR's large-scale surveys of health services utilization and expenditures for US households and for persons with HIV. AHCPR grantees also use these codes to study the linking of electronic patient record information with medical knowledge for

computerized decision support systems to improve the quality of care. The data standards used in data collected and linked by AHCPR are based on those employed by the Bureau of the Census, the American Hospital Association, the Health Resources and Services Administration (Area Resource File), the National Center for Health Statistics, and codes for clinical diagnosis and procedures (such as ICD-9, ICD-9-CM, and CPT-4) in their data sets.

PURPOSE OF STANDARDS:

To make more uniform in meaning the health data collected, exchanged, and analyzed among hospitals, physicians, other health decision-makers, and researchers across geographical areas and institutional boundaries.

The standards that AHCPR uses are intended to facilitate data analysis and use by ensuring greater comparability, quality and accuracy of health care data. In turn, the use of standards increases the automation of health care data for direct patient care, quality measurement, and research. Further, by promoting uniform, accurate, and automated health care data, AHCPR advances medical research (including medical effectiveness and cost effectiveness research) and improves the efficiency of the private sector health care delivery system and quality improvement measurement.

SUBJECTAREAS COVERED:

The standards cover such data as: diagnosis and procedure codes, demographic, employment, economic, health status and other characteristics of survey respondents; the use and cost of services provided by various health care providers; laboratory and imaging standards; and clinical and administrative data for use in computer-based patient record systems and in decision support systems.

STANDARDS ACTIVITIES:

AHCPR promotes the coordination of health care data standards nationally by supporting the meetings of the American National Standards Institute (ANSI), Healthcare Information Standards Board (HISB) and by participating in standards meetings as resources permit; and internationally by sponsoring meetings of standards experts (primarily U.S. European, and Japanese, Canadian, and Australian), coordinated through HISB, and by exchanges of information about current standards activities through research conferences and government liaison. AHCPR participates in HISB's Vocabulary and Codes Working Group and chairs its Legislative and Regulatory Standing Committee.

The purpose of AHCPR support of ANSI HISB is to increase the coordination of private and public sector health data standards activities, to promote the exchange of information with the SDOs of other countries, and to work toward international coordination of health data standards.

AHCPR sponsors and participates in national research conferences to advance the development and use of data standards in electronic medical patient records and health services research. AHCPR staff serve on a number of DHHS and national standards organizations and committees

including the American Medical Informatics Association, International Medical Informatics Association, Computerized Patient Record Institute, ASTM, ANSI, HISB, and the Office of Management of Budget's Interagency Committee for the Review of Racial and Ethnicity (Data) Standards. AHCPR staff supported the development of *Data Elements for Emergency Department Systems, Release* I. *0* (1997) by the Centers for Disease Control and Prevention.

The AHCPR Administrator currently co-chairs the DHHS Data Council and participates in its Committee on Health Data Standards with AHCPR staff participating in its Committee on International Health Data Collaboration, its Interagency Health Privacy Working Group, and its joint Working Group on Telehealth. Under the Committee on International Health Data Collaboration, AHCPR represents DHHS on the Group on Seven Nations (G7) Global Information Infrastructure/Health—Subproject5—Enabling Mechanisms.

AHCPR and the National Library of Medicine have collaborated to undertake a large-scale vocabulary test to determine how well the set of existing vocabularies found in the Metathesaurus of the Unified Medical Language System covered the clinical concepts found in computer-based patient records. The results may be found in Humphreys, et al, "Evaluation... NLM/AHCPR Large Scale Vocabulary Test," *Journal of the American Medical Informatics Association. 1997;4:484-500.*

DATA DICTIONARIES:

The agency uses a number of generally available standard data dictionaries, formats, and coding systems, in developing its data surveys and other standards activities. These include ICD-9, CPT-4, NLM's Metathesaurus, and the U.S. Census Bureau's dictionaries. AHCPR maintains data dictionaries for its major surveys-MEPS and HCSUS.

PUBLICA TIONS AND OTHER DISSEMINA TION:

- *Current Activities of Selected Health Care Informatics Standards Development Organizations (A Compilation), June 1998.*
- *Healthcare Informatics Standards Activities of Federal Agencies (A Compendium), September 1996.*

AHCPR also publishes numerous reports from the Medical Expenditures Panel Survey and the HIV Cost and Utilization Survey. Descriptions of these standards activities and uses are contained in various publications.

For additional information, the AHCPR Clearinghouse's phone number is l-800-358-9295 and the AHCPR's web-site address is http://www.ahcpr.gov.

PARTICIPATION IN ANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS:

AHCPR often participates in HL7, ASTM, WEDI, and X12N meetings as an observer, liaison, and consultant. AHCPR is a member of the Technical Advisory Panel for the development of

the ICD-10-Procedure Coding System led by HCFA. The panel completed its work in 1998. AHCPR participated in the development of the Data Elements for Emergency Department Systems (DEEDS) data set by the Centers for Disease Control and Prevention in 1996-97.

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITY ACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:**

  J. Michael Fitzmaurice is co-chair of the Infrastructure and Cross-cutting Implementation Team (IXIT) that oversees the other HIPAA implementation teams, and a member of the Coding and Classification Implementation Team and the DHHS HIPAA Outreach Working Group. He is the AHCPR representative to the DHHS Committee on Health Data Standards to which the IXIT reports and an AHCPR alternate to the DHHS Data Council through which the HIPAA standards recommendations pass on their way to the Secretary.

  Dr. Fitzmaurice is co-chair of the staff to the Computerized Patient Working Group of the National Committee on Vital and Health Statistics (NCVHS). This working group is charged by NCVHS with preparing the HIPAA-mandated report to "study the issues related to the adoption of uniform data standards for patient medical record information and the electronic exchange of such information" and "to report to the Secretary not later than 4 years after the date of the enactment of the Health Insurance Portability and Accountability Act of 1996 recommendations and legislative proposals for such standards and electronic exchange — (HIPAA Section 263). The report is due in August, 2000.

  Stanley Edinger is a member of the Coding and Classification Implementation Team, and the lead staff to NCVHS' Quality Working Group.

  Jim Summe is the AHCPR representative to the NCVHS' Subcommittee on Populations.

- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:** N/A
- **Plans or Planning Groups Established to Implement HIPAA Changes: N/A**

COMMENTS: N/A

AGENCY: U.S. Department of Health and Human Services
Centers for Disease Control and Prevention & Agency for Toxic Substance and Disease Registry (CDC/ATSDR)

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DATA-REM TED PROGRAMS:

CDC is the nation's primary prevention agency, responsible for preventing disease, injury and disability, and thereby promoting health and quality of life. In collaboration with public health partners and others, it focuses on the prevention of infectious diseases, chronic diseases, injuries, workplace hazards, birth defects and disabilities, and environmental hazards.

CDC is challenged by the ongoing need to provide timely, useful, and epidemiologically-sound information to assist the public health community in developing prevention programs and interventions. A broad variety of data collection methods and systems is in place to help meet this challenge.

At least seven categories of information are needed by CDC:

- Reports of health events affecting individuals;
- Vital statistics on the entire population;
- Information on the health status, risk behaviors, and experiences of populations;
- Information on potential exposure to environmental agents;
- Information useful to public health but obtained by non-public sources;
- Information on existing public health programs; and
- Information on the health care system and its overall effects on health.

STANDARDS EMPLOYED:

CDC has begun an overall process of identifying where relevant surveillance and information systems need standards, and deciding what those standards should be. However, a few CDC programs have begun formal consideration of standards in selected areas. The National Immunization Program (NIP) at CDC worked with Health Level Seven (HL7) to include standard query, response, and update messages for immunization records in HL7's version 2.3, which was published in March 1997. These messages allow standard transmissions of immunization data from healthcare providers to immunization registries and from one registry to

another, NIP considers the establishment of these HL7 messages to be an important factor in the solution to the technical challenges of the registry project.

The National Center for Chronic Disease Prevention and Health Promotion have also worked with HL7 and are involved in a similar process (as NIP) with cancer registries. A meeting was held August 19-21, 1998 with participants from CDC, the North American Association of Central Cancer Registries and HL7 representatives to "explore the feasibility of a standardized electronic exchange protocol for use in cancer registry systems." The summary report for the meeting "Working Toward Implementation of HL7 in NAACCR Information Technology Standards Meeting", was produced in October 1998.

The National Center for Injury Prevention and Control (NCIPC) produced recommended specifications for select data elements in emergency department systems. These specifications are outlined in "Data Elements for Emergency Department Systems, Release 1 .O (DEEDS)." In regards to the standards used for data elements, as stated in the purpose and scope of the DEEDS document: "To the fullest extent possible the specifications for individual data elements in Release 1 .O incorporate existing health data standards, particularly standards for computer-based records."

CDC, in partnership with the Association of Public Health Laboratories, the Association of State and Territorial Health Officials, and the Council of State and Territorial Epidemiologists, recently sponsored the "Electronic Reporting of Laboratory Information for Public Health", a conference held on January 7-9, 1999 in Decatur, GA. The objectives of the conference were to 1) share recent experiences of states, laboratories, and vendors in implementing laboratory reporting 2) examine key issues for expanded laboratory reporting 3) design strategies for expanded adoption, use, and evaluation of electronic reporting. Other issues raised at the conference were the need to develop unified data elements, specific laboratory tests (and codes), and HL7 specifications for data transmission between labs and state/local health departments.

PURPOSE OF STANDARDS:

CDC supports standards because they are seen as critical to the creation of integrated public health surveillance and health information systems, recently identified by strategic planning as CDC's highest priority.

SUBJECTAREAS COVERED:

Areas to be considered for standards development may include: common data elements/standard core variables, software development, transmission, data access, and confidentiality/security. It is intended that standards will eventually influence key areas necessary for integrated surveillance and information systems, potentially affecting the broad array of those systems supported by CDC.

STANDARDS ACTIVITIES:

In order to serve the purpose, to formulate and enact policy concerning the planning,

development, maintenance, and use of integrated public health information and surveillance systems, CDC has formed the *Health Information and Surveillance Systems Board* (HISSB). CDC's principal organizations are represented on the HISSB, which has major subcommittees devoted to general standards and liaison with standards bodies, standards related to Internet applications, and coordination of surveillance activities to name a few. A pre-existing committee of CDC information resource managers, responsible for setting standards in related areas such as computing platforms, connectivity, and information dissemination, is represented on the HISSB.

A subset of the HISSB, the Standards and Liaison (S&L) Committee has been heavily involved in the development of standard data elements and definitions for use primarily in CDC health department systems. The S&L Committee has tackled issues (for core data elements) such as definition of concepts and categories, representation for internal storage, collection mechanisms, user interface, and the dissemination of reports and public use data sets. The recommendations made by the S&L will in inevitably affect the development of new CDC sponsored systems and projects.

In an effort to influence existing systems, the S&L Committee has worked closely with members of the HISSB Integration Project. The integration project is an effort "to tie together the current myriad separate systems used for public health surveillance into a comprehensive solution that facilitates the efficient collection, analysis, and use of data and the sharing of computer software solutions across disease-specific program areas." Members of the integration project have worked closely with the S&L Committee to ensure that proposed standards closely follow the recommendations made in the "Core Data Elements Implementation Guide" (CDE).

DATA DICTIONARIES:

The Standards and Liaison Committee has prepared a common data elements document that details CDC's proposed data collection, storage, electronic data interchange, and dissemination of common data elements approaches used in health information and surveillance systems. The guide has been vetted to external partners and can be downloaded via the intemet at http://www.cdc.gov/data/index.htm. Comments and feedback concerning this document and the proposed standards are welcome.

PUBLICATIONS AND OTHER DISSEMINATION:

CDC has numerous publications including the *Morbidity and Mortality Weekly Report (MMWR)* and *Emerging Infectious Diseases (EID),* both of which are available via Internet. *Integrating Public Health Information and Surveillance Systems,* which describes the basic considerations for formation of the HISSB, is available upon request. The Core Data Elements Implementation Guide is available in hard copy and can be downloaded from the Internet at the address listed above.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZA TIONS:

Susan Abernathy, a member of the NIP staff, was recently (August 1998) elected to the HL7

Board of Directors.

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:**

  Health Information Surveillance Systems Board (HISSB), Executive Secretariat

- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:**

  Health Information Surveillance Systems Board (HISSB), Executive Secretariat

- **Plans or Planning Groups Established to Implement HIPAA Changes:**

  Health Information Surveillance Systems Board (HISSB)

COMMENTS:

The HISSB will oversee the formulation of policy related to standards by instituting and orchestrating a process that will facilitate discussion, develop consensus, and legitimize outcomes. Organizational liaisons with standards bodies have begun and are seen as critical to these bodies developing standards that are informed by the future needs of the public health community.

LINKS WITH OTHER AGENCIES:

Strong internal linkages exist with CDC's National Center for Health Statistics. External linkages are being developed through participation on the DHHS Data Council's Committee on Health Data Standards, and with organizations that maintain or have access to data on health care services and utilization, such as those involved in delivering managed care.

ORGANIZATIONAL MEMBERSHIPS IN STANDARDS DEVELOPMENT ORGANIZATIONS:

- **HL-7** — Susan Abernathy — National Immunization Program
  Denise Koo, M.D. — Epidemiology Program Office
  Dan Pollock — National Center for Injury and Prevention Control
- **ANSIX12** — Roy Gib Parrish — Epidemiology Program Office
- **Computer-based Patient Record Institute (CPRI)** — Ed Kilbourne, M.D. -National Immunization Program Office

AGENCY: U.S. Department of Health and Human Services
Centers for Disease Control and Prevention, National Center for Health Statistics

CONTACT:

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DHHS / CDC / NCHS
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DATA-RELATED PROGRAMS:

The agency serves as the World Health Organization (WHO) Collaborating Center for the Classification of Diseases for North America and is responsible for coordination of all official disease classification activities in the U.S. relating to the International Classification of Diseases (ICD) and its use, interpretation, and periodic revision. This includes maintenance of the ICD-9 for mortality and the clinical modification of ICD-9 (ICD-9-CM) for morbidity. Maintenance for the latter is carried out through the ICD-9-CM Coordination and Maintenance Committee, which was established in 1985 as a forum to discuss possible updates and revisions and is co-chaired by NCHS and the Health Care Financing Administration.

NCHS will be responsible for the implementation of ICD-10 for mortality records in 1999 and for the modification of ICD-10 (ICD-1 O-CM) for morbidity applications. The Collaborating Center is also responsible in North America (NA) for the family of ICD classifications, which includes the International-Classification of Impairments, Disabilities, and Handicaps (ICIDH); the ICIDH is currently under international revision with strong NA input.

NCHS continues to work with the states to develop standard certificates for vital events which include births, deaths, fetal deaths, marriages, divorces, and abortions. These certificates are revised approximately every 10 years, with the next revision planned for implementation in 2002. Evaluation of the current certificates began in September of 1997. NCHS also develops, with state participation, a model law for state registration systems. The standard certificates and model law are the principal means of implementing standardization in the national vital statistics system. Currently, a National Steering Committee convened by NCHS is developing minimum content and transmission standards for the electronic death certificate. Information on these classifica-tions may be found at the NCHS web site at http://www.cdc.gov/nchswww/about/otheract/ icd9/icd9hp2.htm.

NCHS also participates in developing a number of core health data sets in conjunction with interagency task forces and the National Committee on Vital and Health Statistics (NCVHS).

The NCVHS is the external advisory committee to the Department of Health and Human Services; NCHS serves as Executive Secretary to the Committee. The two most prominent core data sets are the Uniform Hospital Discharge Data Set (UHDDS), which is the basis of the hospital discharge data systems in 34 states, and the Uniform Ambulatory Care Data Set (UACDS). Uniform bills, the UB-92 and HCFA-1500, respectively, are a major vehicle for collecting the UHDDS and UACDS. Building on this history of uniform data set development, in 1996, the NCVHS completed a report and recommendations on standardizing 42 core health data elements for enrollment and encounter in 1996; this report was submitted to the HHS Data Council on August 2 1, 1996 and continues to be under review within the Department in the context of adopting standards under the Health Insurance Portability and Accountability Act of 1996. Information about the NCHVS may be found at its web site which is http://aspe.os.dhhs.gov/ncvhs

The agency is responsible for numerous national surveys, including the National Health Intervention Survey (NHIS), the National Health and Nutrition Examination Survey, and national provider surveys. The NHIS is serving as the sampling frame for the Medical Expenditure Panel Survey and, under the Department's integrated survey plan, will serve as the core sampling frame for several departmental surveys. Through this and related mechanisms, NCHS is trying to promote standardized reporting and coding in NCHS surveys, and by example, in similar surveys conducted elsewhere.

STANDARDS EMPLOYED:

The ICD is the official medical classification for disease reporting in the U.S.. The standard certificates for vital records are adopted by all registration areas in the U.S.. Of the core data sets, only the UHDDS has been officially promulgated by DHHS.

PURPOSE OF STANDARDS:

The standards are intended to facilitate data collection and analysis by ensuring comparability across geographic areas and sites of care and enhancing data quality.

SUBJECTAREAS COVERED:

Subject areas are the classification of diseases, causes of death, vital events, and reporting of morbidity data, health events, and other health-related information from individuals, providers, and households.

STANDARDS ACTIVITIES:

Agency personnel participate in activities of the WHO Collaborating Centers for the Classification of Diseases and in development and revision of international classification standards under WHO. Agency personnel also function as one of the four cooperating parties in the United States for development of standard morbidity coding guidelines and, with HCFA, as co-chair of the ICD-9-CM Coordination and Maintenance Committee.

LINKS WITH OTHER AGENCIES:

These activities are coordinated extensively within DHHS, as well as with a broad range of public and private sector organizations.

DATA DICTIONARIES:

The automated systems used in mortality classification are referred to as "dictionaries," translating from medical terms into medical codes. The definitions developed for data elements in the core data sets also represent a type of data dictionary.

PUBLICATIONS AND OTHER DISSEMINATION:

The agency publishes numerous reports, professional papers by staff members, coding instructions for disease classifications, and World Wide Web documents. The annual update of the ICD-9-CM and coding guidelines are made available on CD ROM. Guidelines are also published in conjunction with private sector organizations such as the American Hospital Association. The sentinel NCHS report, Health, United States, is published annually and contains trend data on health status, health care resources, health care expenditures, and utilization of health resources. Natality and mortality data are published in annual volumes and through monthly reports and have recently been included on the NCHS home page. The NCVHS Core Health Data Elements report is on the DHHS home page.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS:

NCHS is a member of the American National Standards Institute Informatics Standards Board (ANSI HISB), Health Level Seven (HL-7), and the ANSI Accredited Standards Committee (ASC)X12. NCHS also is a member of and represents public health and research interests on the National Uniform Billing Committee.

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:**

  Donna Pickett serves as one of the three co-chairs (with the National Library of Medicine and the Health Care Financing Administration) for the Coding and Classification Implementation Team. The team's area of responsibility is codes and classifications for: diseases, injuries, impairments, or other health-related problems, and their manifestations; causes of injury, disease, impairment, or other health-related problems; and actions taken to prevent, diagnose, treat, or manage diseases, injuries, and impairments and any substances, equipment, supplies, or other items used to perform these actions.

  Jane Harman serves as co-chair of the Claims and Encounter Implementation Team. This team recommends formats and data content for health insurance claims, encounters, coordination of benefits, remittance advice, and claim status inquiry.

Phyllis Doulaveris serves as co-chair of the Claims Attachment Team which is recommending standards for 275 and 277 transactions.

Charles Rothwell and ***Michael Kremer*** serve on the Infrastructure Implementation Team, which is coordinating the work of the other teams, addressing crosscutting issues, and developing the data dictionary.

Marjorie Greenberg and ***Lynnette Araki*** serve as principal and alternate, respectively, on the departmental Health Data Standards Committee, which oversees the HIPAA implementation teams for the HHS Data Council. Ms. Greenberg also serves as Executive Secretary of the National Committee on Vital and Health Statistics and Head of the WHO Collaborating Center for the Classification of Diseases for North America.

- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:**

  On November 2-3, 1998, NCHS/CDC, in conjunction with the Agency for Health Care Policy and Research (AHCPR) and the NCVHS, sponsored an invitational workshop "Implications of HIPAA's Administrative Simplification Provisions for Public Health and Health Services Research." In response to recommendations from that workshop NCHS is working with workshop participants to establish a consortium for representing health and health services research data needs in the standards process and ensuring that priority information needs are addressed in on-going standards maintenance efforts. Information about the workshop proceedings is available at a web site, http://www.lewin.com/hipaa.

- **Plans or Planning Groups Established' to Implement HIPAA Changes:** N/A

COMMENTS: N/A

AGENCY: U.S. Department of Health and Human Services
Food and Drug Administration

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DATA-RELATED PROGRAMS:

The Food and Drug Administration (FDA) is responsible for ensuring that foods are safe, wholesome, and sanitary; human and veterinary drugs, biological products, and medical devices are safe and effective; and cosmetics and electronic products that emit radiation are safe. Regulatory decisions must be based on information that is complete, accurate, and readily available, so that large amounts of data that are collected from pre-market approval submissions and post-market surveillance activities must be maintained and available for analysis whenever and wherever required. To that end, FDA designs administrative, scientific, and technical information systems in support of its regulatory programs.

STANDARDS EMPLOYED:

The FDA utilizes standards developed "in-house" which it promulgates and enforces, such as the quality standards under the Mammography Quality Standards Act of 1992 and Section 204 of the FDA Modernization Act of 1997 that adds a system for recognizing national and international standards in product reviews. The FDA may recognize all or part of an appropriate standard established by a nationally or internationally recognized standards development organization. Examples include the utilization of the Coding Symbols for a Thesaurus of Adverse Reaction Terms (COSTART) developed and maintained by the FDA's Center for Drug Evaluation and Research and the World Health Organization Adverse Reaction Terminology (WHOART), developed and maintained by the WHO, and the International Electrotechnical Commission (IEC) 60601 series of standards.

PURPOSE OF STANDARDS:

Standards are used as a basis for regulatory assessments, providing measures for compliance with regulatory requirements, providing guidelines of practice where formal regulations have not been promulgated, and for developing consensus on approaches for producing safe products in new and emerging technical areas.

SUBJECTAREAS COVERED:

The FDA participates in standards development activities on standardizing terminology, development of consensus for measuring performance characteristics of medical devices, and standards which provide metrics for quality assurance that can provide less onerous approaches to assuring the safety and/or effectiveness of regulated products.

STANDARDS ACTIVITIES:

The FDA participates in the development of national and international consensus standards and voluntary guidelines through interaction with appropriate national and international standards committees. Emphasis is placed on efforts aimed at avoiding or minimizing redundancies in standards development activities, developing uniform terminology, and developing standards where conformance with the standard enables less onerous regulatory requirements.

DATA DICTIONARIES: N/A

PUBLICATIONS AND OTHER DISSEMINATION:

The FDA maintains an updated record of draft and final documents at its web site, http://www.fda.gov.

PARTICIPATION IN ANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS:

The FDA participates in activities of the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH) and the Global Harmonization Task Force (medical devices). The FDA is a member on the ANSI Medical Device Standards Board, the ANSI Management Board, and many of the ANSI-accredited standards development organizations. These activities are described in an annual report.

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:** N/A
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:** N/A
- **Plans or Planning Groups Established to Implement HIPAA Changes:** N/A

COMMENTS:

Many of the FDA's medical, scientific, and regulatory staff participate in standards-setting bodies as either representatives of their professional organizations or as representatives of the FDA. Participation varies as to the level of pertinence and potential impact on either a program area within the agency or the agency as a whole.

AGENCY: U.S. Department of Health and Human Services
Health Care Financing Administration

CONTACT:

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Office of Clinical Standards and Quality
Health Care Financing Administration
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DATA-RELATED PROGRAMS:

HCFA is involved in a number of national health data initiatives. These cover the development of core data sets as well as quality measures, financial indicators, measures of beneficiary satisfaction, and measures of access to care for several settings of care, including long-term care, home health, end-stage renal disease, managed care, and fee-for-service acute care. Data is collected both electronically from providers as well as through medical record abstractions. The Agency is currently moving towards the development of significant on-line analytic processing capabilities to provide greater utility to the Medicare and Medicaid program databases which it maintains.

STANDARDS EMPLOYED:

HCFA employs standards developed by several standards development organizations (SDOs) including American Standards Committee (ASC) X12N, Health Level 7 (HL7), ASC X3, and others. Currently these standards are focused primarily on data transmission, but there is an increasing interest in data models and data administration standards.

PURPOSE OF STANDARDS:

HCFA utilizes standards in its data acquisition activities, in development of its Conditions for Coverage for participation in Medicare by providers, and as part of its reimbursement process.

SUBJECTAREAS COVERED:

These standards cover all aspects of medical care and health status for the 37 million Medicare beneficiaries. This includes reimbursement activities from providers who are paid by HCFA for Medicare services and selected submission under states' Medicaid claims. This includes over 1.2 million providers, their agents, and vendors.

STANDARDS ACTIVITIES:

HCFA personnel participate in ASC X12N, HL7, ICD-1 O-PCS (Provider Coding System), ICD-9-CM Committees (partnering with the National Center for Health Statistics), ASC X3, IS0 Technical Committee 2 1 5/Health Informatics, ISO/JTC1 Subcommittee 32/Data Management, and several other groups involved in health data standards. Standards are coordianted extensively with DHHS, by formal policy-setting processes, and with other agencies, states, insurers, providers, and vendors.

DATA DICTIONARIES:

HCFA currently provides a number of clinical data dictionaries, developed by the Office of Clinical Standards and Quality, on its Internet site.

PUBLICATIONS AND OTHER DISSEMINATION:

HCFA promulgates its standards through several media, including print, magnetic, and the World Wide Web.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS:

HCFA is active in standard setting initiatives as described in the "Standards Activities" section.

HEALTHINSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELA TED ACTIVITIES:

HCFA is the lead agency in the development of HIPAA regulations and co-chairs all of the federal workgroups in this area. HCFA also has a significant staff presence on the workgroups, and, as a major payer, is working internally to implement the proposed standards.: HCFA also has staff on each of the NCHVS workgroups in support of HIPAA.

- **Key Personnel Assigned to HIPAA Implementation:** N/A
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:** N/A
- **Plans or Planning Groups Established to Implement HIPAA Changes:** N/A

COMMENTS:

AGENCY: U.S. Department of Health and Human Services
Health Resources and Services Administration (HRSA)

CONTACT:

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DA TA-RELA TED PROGRAMS:

HRSA promotes primary care and other services to vulnerable populations, principally through grants to States, localities, academic institutions, and community-based organizations. Grantees report aggregate data on clients served and services provided.

HRSA sponsors the *Area Resource File* (ARF), a county specific health resources information system. The existing data elements from the externally provided data sources are used and include geographic descriptors, health professions information (including training), health facilities information, utilization levels for hospitals, health care expenditures, and population characteristics and economic data. HRSA also maintains the *Practitioner Data Bank* established by Congress to direct discrete inquiries into and scrutiny of specific areas of a practitioner's license, professional society memberships, Medical malpractice payment history, and record of clinical privileges.

HRSA is very interested in the current work on standardizing encounter and enrollment data, which will facilitate monitoring access to care. HRSA has participated as a commenter on a number of data standardization initiatives, including the *Healthplan Employers Data and Information Set* (HEDIS) indicators; the identification of a consensus-based set of ICD-9 codes that can be used to measure inadequate primary care; and the current DHHS study of state and local public health expenditures and capacity for personal health services.

STANDARDS EMPLOYED:

HRSA is a user but not a setter of data standards. In the development of grantee reporting requirements and other data systems, HRSA reviews coding schemes and adopts them as appropriate. For example, the National Practitioner Data Bank uses the Harvard University Foundation Allegation of Negligence coding scheme. In reviewing and selecting existing coding systems, HRSA consults widely with relevant parties before implementing reporting formats.

PURPOSE OF STANDARDS: N/A

SUBJECTAREAS COVERED: N/A

STANDARDS ACTIVITIES: N/A

DATA DICTIONARIES: N/A

PUBLICATIONS AND OTHER DISSEMINATION: NIA

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS: NIA

HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation: N/A**
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts: N/A**
- **Plans or Planning Groups Established to Implement HIPAA Changes: N/A**

COMMENTS: N/A

AGENCY: U.S. Department of Health and Human Services
Indian Health Service (IHS)

CONTACTS:

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DATA-RELATED PROGRAMS:

IHS has a number of efforts in progress to develop health status and care indicators, which it then encourages tribes to adopt.

STANDARDS EMPLOYED:

The agency generally follows DHHS standards (e.g. departmental ambulatory medical data and discharge data sets and molds its forms and processes to follow HCFA's model in most cases.) Tribes are encouraged, but not required, to use the core data set IHS has adopted. Tribes have considerable flexibility and variability in what services they receive, how they pay, and how they report.

PURPOSE OF STANDARDS:

The standards developed by the agency are used as part of the agency's usual processing and related functions. External standards are applied as deemed useful. The legislative and regulatory mandates for this activity are the authorization acts for the agency, but this legislation does not mention standards; it simply directs the agency to ensure services.

SUBJECTAREAS COVERED:

The subject areas covered are various aspects of the health status of, and medical care provided to, members of Indian tribes, either directly by this agency or tribes, or under contract by private providers and insurers. Community health and infrastructure are affected as well as clinical care.

STANDARDS ACTIVITIES:

Agency personnel do not participate in standards-setting bodies although they serve on DHHS work groups. IHS generally tries to follow standards and guidelines developed elsewhere, especially within DHHS.

DATA DICTIONARIES:

None. IHS has developed a core data set which tribes are encouraged, but not required, to use.

PUBLICATIONS AND OTHER DISSEMINATION:

The standards are promulgated by publication in the *Federal Register,* by inclusion in manuals, and by less formal communication with providers and tribal leaders. To promote the use of standards or guidelines by tribes, the agency holds meetings with tribes and usually sends out letters to tribes and regional officials soliciting review and comments. Such solicitations are sometimes published in the *Federal Register* as well. Information on the health care data systems is available on the World Wide Web at, http:\\www.ihs.gov.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZA TIONS: N/A

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELATED ACTIVITIES: N/A

- **Key Personnel Assigned to HIPAA Implementation:** N/A
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:** Participate on DHHS Data Council and on DHHS standards work groups.
- **Plans or Planning Groups Established to Implement HIPAA Changes:** N/A

COMMENTS:

Measures the agency takes to enforce or encourage compliance with standards: IHS enforces compliance with standards by declining requests for contract renewal from providers and vendors who do not follow the agency's requirements.

Measures the agency takes to assess the effects of standards: the agency assesses the effects of standards by developing baseline measures and performance indicators and encouraging their adoption by IHS providers and by tribal contractors. These measures include health status, health practices, community involvement, some financial elements, some Healthy People 2000 objectives, some HEDIS indicators, and some community-specific elements.

The agency's office of Public Health has focused more on NCHS reporting than on HCFA reporting; much payment data HCFA would collect is not collected for IHS beneficiaries.

AGENCY: U.S. Department of Health and Human Services
National Institutes of Health, National Cancer Institute, International Cancer Information Center

CONTACT:

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International Cancer Information Center
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Bethesda, MD 20814

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E-mail: su@icic.nci.nih.gov

DATA-RELATED PROGRAMS:

The International Cancer Information Center's (ICIC) mission is to effectively disseminate state-of-the-art information about cancer treatment and research worldwide. The major long term goal of the ICIC is to provide appropriate information about cancer treatment and research to all persons and organizations with a need for the information. Strategies for achieving the program goals include removing technological, cost, and language barriers to obtaining ICIC information products; defining the universe of potential users of information about cancer treatment and research and the needs of groups within that universe; and developing a plan for reaching groups within that universe.

Towards this end, the ICIC disseminates the *Journal of the National Cancer Institute* bimonthly and provides two databases containing information about cancer research and treatment: the *Physician Data* Query (PDQ) and the CANCERLIT database. ICIC provides electronic access to this data in a variety of ways including online access, facsimile access, and access via the Internet. ICIC is currently building a universal database server that will contain and disseminate all scientific information collected by or created in the ICIC.

STANDARDS EMPLOYED:

Medical data standards are not used in creating the ICIC information collection, but are useful in accessing that collection. They include a wide variety of standards such as ICD-9, CPT-4, Snomed, ACR/NEM, HL7, etcetera.

PURPOSE OF STANDARDS:

The standards described above, and others, will allow individual users or automated medical information systems to interface directly to ICIC data using native nomenclatures.

SUBJECT AREAS COVERED:

The standards cover data including health status, the use and cost of health services, laboratory and imaging standards, and general clinical data for use in computer-based patient record

systems.

STANDARDS ACTIVITIES:

ICIC staff monitor standards activities through the Health Information Standards Planning Panel, the White House Information Infrastructure Task Force — Health Information Applications Working Group, and through G7 activities.

DATA DICTIONARIES:

The ICIC universal database will support retrieval using a wide range of standard nomenclatures as stored in the National Library of Medicine's Unified Medical Language System (UMLS).

PUBLICATIONS AND OTHER DISSEMINATION: N/A

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS: NIA

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:** N/A
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:** N/A
- **Plans or Planning Groups Established to Implement HIPAA Changes:** N/A

COMMENTS: N/A

AGENCY: U.S. Department of Health and Human Services
National Institutes of Health, National Library of Medicine

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DATA-RELATED PROGRAMS:

Although its basic services are focused on acquisition, organization, preservation, and access to the published literature, NLM also has several programs related to biomedical and health data:

- NLM's National Center for Biotechnology Information builds and maintains GenBank, a huge data base of molecular sequence data, and develops information systems that allow researchers to contribute to the data base, to use it to aid their research, and to link it to related biological information sources.
- The Library collaborates with other Federal agencies to build and make available data banks on the toxicological and environmental effects of chemicals and on AIDS clinical trials and experimental drugs. NLM was recently assigned lead responsibility by the Director of NIH to build a comprehensive clinical trials database.
- The Visible Human project has created high-resolution volumetric data sets for entire human male and female cadavers.
- The Unified Medical Language System (UMLS) project has developed a Metathesaurus that integrates concepts and terms from about 50 different health-related vocabularies and classifications in a single database format. Developers of health data systems can use the Metathesaurus as a convenient and uniform source of controlled vocabulary for data creation applications.
- NLM's Extramural Grants program has a 25-year history of funding research related to the development of clinical information systems and automated patient data. More recently, as a participant in the multi-agency High Performance Computing and Communications (HPCC) program, the Library has funded research and development regarding health-related applications of the National Information Infrastructure, including patient record systems, the transfer of data between the health care and public health systems, and ensuring the confidentiality of electronic health data.

STANDARDS EMPLOYED:

NLM uses a wide range of national and international standards for bibliographic and publication data, including SGML (Standard Generalized Mark-up Language), standards for bibliographic references, cataloging records, holdings data, and abbreviations of titles of journal articles.

The Library also uses the Abstract Syntax Notation 1 (ASN-1) in the distribution of molecular biology data and has begun experiments with the use of XML for the distribution of UMLS knowledge sources.

PURPOSE OF STANDARDS:

NLM employs standards to facilitate the integration of the Library's bibliographic, molecular biology, and vocabulary data into information systems throughout the world and the incorporation of information generated elsewhere into the Library's systems and services.

SUBJECTAREAS COVERED:

Standards apply to published literature; molecular biology data; chemical, toxicological, and environmental health data; and biomedical and health-related nomenclature.

STANDARDS ACTIVITIES:

NLM is a voting member of the National Information Standards Organization and from time to time chairs or participates in committees developing specific library and information science-related standards.

NLM currently chairs the DHHS Data Council Working Group on International Health Data Collaboration: G7 Nations, and represents NIH on the DHHS Data Council's Committee on Health Data Standards and Interdepartmental Health Privacy Working Group.

From 1995-97, NLM provided support for the development and extension of the DICOM standard and related work on aligning HL7 and DICOM.

NLM participated in the ANSI HISPP (Health Informatics Standards Planning Panel) Vocabularies and Codes Working Group.

In 1996-7, NLM and AHCPR sponsored an Internet-based Large-scale Vocabulary Test to determine the extent to which a set of controlled vocabularies cover the concepts and terms needed in health care and public health applications. The results of the test, were published in the November 1997 issue of JAMIA, The Journal of the American Medical Informatics Association. The results indicate that the set of existing vocabularies contain a substantial majority of the concepts required to describe patient conditions in computer-based patient records. A combination of vocabularies provides substantially better coverage of these concepts than any single vocabulary does.

NLM has initiated a collaborative effort involving the American Medical Association, the College of American Pathologists, and the National Center for Health Statistics to develop standard formats for mapping detailed clinical vocabularies to statistical and billing codes.

DATA DICTIONARIES:

NLM maintains data dictionaries for its bibliographic, thesaurus, molecular biology, and chemistry and toxicology data.

The UMLS Metathesaurus will be the vehicle for public distribution of HL7's decisions about which vocabulary terms are valid values for specific parts of HL7 messages.

PUBLICATIONS AND OTHER DISSEMINA TION:

NLM maintains data dictionaries for its bibliographic, thesaurus, molecular biology, and chemistry and toxicology data.

The UMLS Metathesaurus will be the vehicle for public distribution of HL7's decisions about which vocabulary terms are valid values for specific parts of HL7 messages.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS:

As stated above:

- NLM is a voting member of the National Information Standards Organization, an ANSI-accredited SDO.
- The UMLS Metathesaurus will be the vehicle for public distribution of HL7 decisions about which vocabulary terms are valid values for specific parts of HL7 messages. HL7 is an ANSI-accredited SDO.

HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:** Betsy L. Humphreys is co-chair of the Codes and Classifications Implementation Team for HIPAA Administrative Simplification.
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:** N/A
- **Plans or Planning Groups Established to Implement HIPAA Changes:** N/A

COMMENTS: N/A

AGENCY: U.S. Department of Defense

CONTACT:

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DATA-RELA TED PROGRAMS:

This office participates in the Department of Defense's data standardization program by developing standards needed to support the changing business of the Military Health System (MHS). This includes data to support such activities as medical readiness, force health protection, managed care, immunization, credentials, and patient-based records keeping. The MHS is also a Tri-service activity including the Army, Navy, and Air Force health/medical communities. The Office of the Assistant Secretary of Defense (Health Affairs) is partnering with the Department of Veterans Affairs, Department of Health and Human Services, and others to develop a government computer-based patient record. This office publishes as a directive the MHS Glossary that is based on health and medical terms and definitions used Department of Defense-wide. Glossary and data standards activities are tied to the formal forms and reports management programs. An enterprise approach to data standards development and use is taken from the policy and management level to modeling functional requirements for computer applications.

STANDARDS EMPLOYED:

Health industry standards are incorporated and used by the MHS as appropriate Health industry standards are reviewed and applied to influence Military Health System standards models and Department of Defense standards. For example, American Standards Committee Xl2 series, Health Level 7, Health Insurance Portability and Accountability Act, and other health industry standards are used.

PURPOSE OF STANDARDS:

The standards are used in MHS policy, forms, and reports management programs and computer applications to achieve better sharing of data and interoperability of systems, both within the MHS and among the other DoD and civilian systems, and in the selection process to acquire

commercial off-the-shelf products. The one set of standards are organized into a formal directive and published as a MHS Glossary.

SUBJECTAREAS COVERED:

The subject areas covered by the data administration group include all aspects of military health force protection, readiness and managed care. This includes data needed to provide and manage clinical services, resources, to provide medical logistics support, and to make executive decisions.

STANDARDS ACTIVITIES:

Standards activities include developing new standards and coordinating them across the three services, with other DoD functional areas, the Department of Veterans Affairs, the Department of Health and Human Services, the Department of Commerce, and with industry. Standards activities begin at the management level where policy, directives, manuals, and other communications use standard terms and definitions that are the basis of formal data standards. Standards activities are imbedded in the formal forms and reports management programs. These standards are used in business processes and also include assisting developers to implement the standards in the computer systems. This office also works with the Federal Chief Information Officer standards committee. The Military Health System Data Program is building a Data Registry. This project includes components of the Health Insurance Portability and Accountability Act, Military Health System standards, Department of Defense standards, and others. The Department of Health and Human Services and the Environmental Protection Agency are partners with the Military Health System Data Program Office in this data registry project.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS:

The Department of Defense and the Military Health System work extensively in ANSI accredited and other standards development organizations. Work is conducted by providing guidance and by voting in ASC Xl 2 insurance data modeling for electronic data interchange transactions and other groups. Work is also conducted on the model-based strategic planning for ASC Xl2 future direction. The office is completing a comparative analysis with the Department of Defense, Military Health System functional area models and the Health Level-7 model for exchanging data among clinical systems. The office also provides data models to various standards development organizations via public access to the Internet site.

DATA DICTIONARIES:

The data dictionary project is part of the overall methods and technology framework employed to support the full data life cycle. This is part of a data architecture that includes a top down approach from management glossaries to computer system data dictionaries. Migration system data dictionaries are registered in the Defense Data Dictionary system along with DOD-approved standard data elements. Both approved and developmental data elements are recorded in the MHS Functional Area Model – Data (FAM-D). All new data dictionaries are supposed to be model-based and drive from logical models to physical models to build reusable components in a

variety of implementations. Some data dictionary projects are now part of the enterprise data warehouse project where data standards are being implemented from a different view.

PUBLICATIONS AND OTHER DISSEMINA TION:

The main source of publications is the health information resources service. This online capability is at http://www.hirs.osd.mil/mhss/. Version control of some publications is managed to incorporate new business practices and data standards. The primary products are the Military Health System Functional Area Model-Data and Military System Functional Area Model-Activity. The functional area models are the foundation of overall data quality activities.

HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:**

  Marco Johnson is the DoD MHS voting representative to the Federal Inter-agency Health Data Standards Committee hosted by the Department of Health and Human Services. Mr. ***Glenn Sperle*** and ***Lloyd Anderson*** are Senior Operations Researchers working on DHHS teams and serve as coordinators of the DoD members to HIPAA Implementation Teams.

- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:**

  The DoD Military Health System conducts model-based reviews of the HIPAA transaction standards and conducts mapping and gaping analysis of the HIPAA transactions to the current DoD, MHS data standards and measures the impact of the transactions to the operational automated information systems to determine the degree of change needed.

- **Plans or Planning Groups Established to Implement HIPAA Changes:**

  DoD HIPAA assessment and planning sessions take place as part of the chartered MHS Data Program Work Group. Specific staff is identified from all parts of the Military Health System organization and all partners (managed care contractors). Issues are identified and being worked. The data staff has alerted the full organization about HIPAA and work sessions are under way.

COMMENTS:

This office recommends that a Federal agency be designated as custodian of a Federal Health Services model. This model should tie together the Federal Health business across all Departments. The States can use this model. This office recommends that the Military Health System Model be used as a starting point. This model was first developed in 1990 and as of January 1999 continues to be validated by the Health community. This model is being used to jump-start the Government Computer-based Patient Record (GCPR) project. The GCPR project includes the Department of Defense, Department of Veterans Affairs, The Department of Health and Human Services, and others.

This recommendation would save the rest of the health standards community thousands, perhaps millions of hours of work and also streamline the standards process. This publication is already being used as government furnished information for acquisition purposes in the Department of Defense, Assistant Secretary of Defense for Health Affairs. The data quality in the government will increase if the entire process of developing and publishing data standards, terms, and definitions, etc. were model based.

This office believes it is imperative that the Agency for Health Care Policy and Research be the source for model-based policy and model-based research. Tools and techniques are in place and products are available for validation by the Federal health community. Now is the time to respond to this health business need. This will allow structured research to support policy options.

AGENCY: U.S. Department of Energy

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DA TA-RELA TED PROGRAMS:

The Office of Environment, Safety and Health accident recordkeeping and reporting program includes collection and analysis of DOE and DOE contractor reports of injuries, illnesses, and other accidents that occur during DOE operations. It also includes exposure information such as hours worked, miles driven, property valuation, etc. that can be used to calculate accident rates. This information is measured and tracked in the Computerized Accident/Incident Reporting System (CAIRS). Incidence rates and the number of cases available from this system are analyzed to identify trends, potential hazards, and prioritize means for improvement of safety and health performance.

STANDARDS EMPLOYED:

The recordkeeping criteria for occupational injuries and illnesses are based on OSHA guidelines for recording occupational injuries and illnesses. Property and vehicle damage reporting is value based. The current thresholds for property and vehicle damage reporting are $5,000 and $1,000 respectively. Occupational injury and illnesses data is coded by occupation, nature of the injury, part of body affected, source of the injury/illness, and type of injury/illness.

PURPOSE OF STANDARDS:

The standards are used to facilitate comparisons with data collected from DOE and external data sources.

SUBJECTAREAS COVERED:

The subject areas covered include all recordable accidents (injury/illness, property, and vehicle) that occur during DOE operations.

STANDARDS ACTIVITIES:

Development of standard codes for environment, safety, and health databases.

DATA DICTIONARIES:

A users' manual and coding manual is available for CAIRS. These documents identify data fields and codes.

PUBLICATIONS AND OTHER DISSEMINATION:

Occupational Injury and Property Damage summary reports are summarized and made available online following the end of each quarterly 'collection period. The annual summary report includes summary tables and analysis. Access to CAIRS is available to staff of DOE and DOE contractor organizations. Access to sensitive data requires special authorization. Through the database users can access CAIRS Standard Reports, Basic Reports, Logs, and Search and Distribution. The Standard Reports provides easy access to preformatted reports. The CAIRS logs allow users to easily prepare listings of accident cases by organization, date, and type of case. The CAIRS Basic reports allow users some flexibility in determining the data elements to be included in each report. The CAIRS search and distribution option provides the capability of performing detailed searches of the CAIRS data and displaying the results in user defined reports.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS: None reported.

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:** None reported.
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:** None reported.
- **Plans or Planning Groups Established to Implement HIPAA Changes:** None reported.

COMMENTS:

AGENCY: U.S. Department of Justice
Office of Justice Programs, Bureau of Justice Statistics

CONTACT:

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810 7" Street NW
Washington, D.C. 2053 1

Phone: (202) 6 16-3494
Fax: (202) 307-1463
E-mail: randm@ojp.usdoj .gov

DATA-RELATED PROGRAMS: National Crime Victimization Survey (NCVS). DOJ is also implementing a State prison healthcare information survey. The contact point for that survey is Ms. Paula Ditton. Her telephone number is (202) 305-9014. She can also be contacted at her E-mail address dittonp@ojp.usdoj .gov.

STANDARDS EMPLOYED: N/A

PURPOSE OF STANDARDS: NIA

SUBJECTAREAS COVERED:

Data covered in the NCVS include injuries inflicted during crimes of violence including: nature of the injuries; medical treatment received; medical insurance coverage; and days lost from work. The survey of state and local prisons provides data on the health problems of inmates as well as types of treatment they receive.

STANDARDS ACTIVITIES: N/A

DATA DICTIONARIES:

Data from the NCVS is available through the National Archive of Criminal Justice Data (NACJD), l-800-999-0960.

PUBLICATIONS AND OTHER DISSEMINATION:

Publications are available online from the Bureau of Justice Statistics World Wide Web site: www:ojp.usdoj.gov/bjs, or from the National Criminal Justice Reference Service, 1-800-732-3277. A report summarizing the mental health data obtained from the state prison survey will appear in the summer of 1999.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZA TIONS: N/A

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELA TED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation: N/A**
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts: N/A**
- **Plans or Planning Groups Established to Implement HIPAA Changes: N/A**

COMMENTS: N/A

AGENCY: U.S. Department of Labor
Bureau of Labor Statistics

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Phone: (202) 606-6304
Fax: (202) 606-6310

DATA-RELATED PROGRAMS:

The Bureau of Labor Statistics (BLS) occupational safety and health statistics program includes the annual Survey of Occupational Injuries and Illnesses that reports information on non-fatal work-related accidents and the Census of Fatal Occupational Injuries. The program provides information on the number and incidence of job-related injuries, illnesses, and fatalities by Standard Industrial Classification (SIC). For non-fatal injuries and illnesses that involve recuperation away from work, demographic data about the injured and ill workers is reported along with details about the circumstances of the injuries and illnesses. Information about workplace fatalities are available by occupation and other worker characteristics, equipment being used, and circumstances of the event.

STANDARDS EMPLOYED:

The BLS occupational injury and illness data is classified by industry using the Standard Industrial Classification (SIC) system. The occupations of the injured and ill workers are coded using the Bureau of Census occupational classification system. The injury and illness characteristics (nature of injury / illness, part of body affected, source of injury / illness, and event or exposure leading to the injury / illness) are classified according to the BLS Occupational Injury and Illness Classification system.

PURPOSE OF STANDARDS:

The standards allow descriptive information about work related injuries and illnesses to be classified in formats that can be tabulated, compared, and published.

SUBJECTAREAS COVERED:

The Survey of Occupational Injuries and Illnesses gathers data on non-fatal occupational injuries and illnesses that occur during the reference year to workers in private industry, except on farms with fewer than 11 employees. The Census of Fatal Occupational Injuries covers fatal traumatic injuries during the reference year to workers in both private industry and the public sector including the self-employed.

STANDARDS ACTIVITIES: NIA

DATA DICTIONARIES: N/A

PUBLICATIONS AND OTHER DISSEMINA TION:

News releases for the Survey of Occupational Injuries and Illnesses are available in two releases: 1) case counts and incidence (frequency) rates by industry in December following the reference year, and 2) case characteristics and worker demographic profiles the following April. The news release for the Census of Fatal Occupational Injuries is available in August following the reference year. A bulletin, *Occupation Injuries and Illnesses.. Counts, Rates, and Characteristics*, that reports comprehensive data from the survey is published for each reference year. An annual report, *Fatal Workplace Injuries: A Collection of Data and Analysis*, reports detailed fatality information and includes research articles about high-risk jobs. Extensive tables reporting information on both fatal and non-fatal job-related injuries and illnesses is available on the Internet at: http://stats.bls.gov/oshcont.htm.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS: Member, ANSI Z16 committee.

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:** N/A
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:** N/A
- **Plans or Planning Groups Established to Implement HIPAA Changes:** N/A

COMMENTS: N/A

AGENCY: U.S. Department of State

CONTACT:

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DATA-RELA TED PROGRAMS:

The Office of Medical Services is the health care organization with the responsibility mandated by the Office of the Director General of the U.S. Foreign Service to maintain and promote the health of FS employees and their families serving in over 250 locations worldwide. This includes health maintenance activities, acute health care services, and facilitating access to health care.

The Department of State is engaged in developing two data base management systems to support this health care program. The first system, in testing now, is the Worldwide Health Resources, Risks and Recommendations System, designed to integrate legacy data together with disparate information from over 150 overseas medical program sites. In early development is the Department of State Electronic Medical Record system, integrating an Oracle dbms and a COTS interface with imaged medical records and customized laboratory and radiology dbms.

STANDARDS EMPLOYED:

DoS is committed to use of health industry standards in managing data. The National Library of Medicine's Unified Medical Language System (UMLS) will be applied, as well as HL7 transfer protocols. Other DHHS, and JCAHO information management standards and guidelines are sought for application as relevant. ICD-9-CM standards are used in disease, condition, and procedure reporting.

PURPOSE OFSTANDARDS:

Compliance with data standards will be essential in data analysis within the DoS' health care organization, as well as allowing comparability to other appropriate U.S. patient population data residing with other organizations such as CDC, etc.

SUBJECTAREAS COVERED:

Capability of foreign health care systems worldwide, located in areas where FS personnel live

and work, to support adequate care. Capability of DoS Medical Program staffed in 56 locations worldwide, to support adequate care, including referrals, hospitalizations, and medevacs. Health risks and recommendations unique to foreign work environments. Documentation of all Medical Program patient encounters.

STANDARDS ACTIVITIES:

Development of medical informatics data standards for the Department of State Office of Medical Services programs, across all existing and in-development database management systems.

Participates in the interagency Data Working Group (DAWG). Participate in UMLS. No involvement in standard setting bodies at this time. Standards activities are monitored by Division of Medical Informatics staff.

DATA DICTIONARIES:

Will use UMLS data dictionary, once design of Department of State Electronic Medical Record System is detailed and fixed. Will assess whether a unique DoS Data Dictionary System should be defined before complete development of EMR.

PUBLICATIONS AND OTHER DISSEMINATION:

Will be published in Department of State policy and procedure documentation. Will be available when future web site is up.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS: N/A

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:**

  Jennifer Grise, as above, until staff is expanded.

- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:**

  Medical record imaging standards for the organization are currently under review. Recommendations for organization in draft. Transaction standards for COTS product for EMR set in 1997 for selection of vendor. Work on specific compliance to begin in February 1998

- **Plans or Planning Groups Established to Implement HIPAA Changes:**

  To be addressed in Information Strategic Plan, estimated completion in late 1998.

COMMENTS: N/A

AGENCY: U.S. Department of Transportation
National Highway Traffic Safety Administration, Emergency Medical Services Division

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DATA-RELATED PROGRAMS:

The agency supports development of twelve National Standard Curricula for emergency medical services and emergency medical technicians. The agency supports the linkage of information from police crash reports, ambulance run sheets, hospital discharge data, and coroners reports. In cooperation with other agencies and parties, the agency developed the Uniform Pre-Hospital Data Set that in a consensus process defined data elements that should be used on ambulance run reports.

STANDARDS EMPLOYED:

The EMS Division develops voluntary guidelines for the delivery of pre-hospital emergency care in cooperation with states and professional organizations. These standards are adopted by states and incorporated into state required training materials. The guidelines are intended to improve the quality of emergency medical care by incorporating best practices into training materials. The National Standard Curricula provide continuity of training materials for all states and territories.

DOT has a congressional mandate regarding emergency medical services (PL 89-564,1966).

PURPOSE OF STANDARDS:

Each State has the responsibility of defining the State requirements for training of emergency medical technicians. The States generally adopt the DOT National Standard Curricula as the State required level of training. Although they are guidelines, the National Standard Curricula promote uniformity across the country and limit state-to-state variation in the scope of practice and in educational programs.

SUBJECTAREAS COVERED:

- National Standard Curricula for training emergency medical technicians;
- Quality Assurance for emergency medical services;
- Future trends in out-of-hospital emergency medical care;
- Projected pre-hospital research agenda;
- State assessments of emergency medical services;
- The National EMS Education and Practice Blueprint; and
- Public education concerning bystander care for the injured.

STANDARDS ACTIVITIES:

Agency personnel participate in standards-setting bodies such as the ASTM F30 Committee on Emergency Medical Services. The EMS Division uses a consensus building process for development of National Standard Curricula and other system operation guidelines.

LINKS WITH OTHER AGENCIES:

The EMS Division works closely with HRSA's Maternal and Child Health Bureau in administering the Emergency Medical Services for Children's program. The Division participates on the Federal Interagency Committee on Emergency Medical Services as well as with other Federal agencies and professional organizations on its various EMS projects.

DATA DICTIONARIES:

The Uniform Pre-Hospital Data Set which proposes guidelines for data collection in Ambulance Run Reports.

PUBLICATIONS AND OTHER DISSEMINATION:

- Twelve National Standard Curricula,
- The EMS Agenda For the Future,
- The EMS Agenda for the Future Implementation Guide,
- The Guidelines for Quality Improvement Programs,
- The First There...First Care Program,
- The Make the Right Call Campaign, and other documents specific to emergency medical services activities.

The EMS Division's World Wide Web home page is:
http://www.nhtsa.dot.gov/people/injury/ems.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS: As invited.

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:** N/A
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:** N/A
- **Plans or Planning Groups Established to Implement HIPAA Changes: N/A**

COMMENTS:

Assessments of ***Effects.*** The EMS Division is sponsoring research on EMS to assess the effect of emergency medical care on morbidity and mortality.

AGENCY: U.S. Department of Veterans Affairs
Veterans Health Administration

CONTACTS:

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DATA-RELATED PROGRAMS:

As the second largest of the 14 Cabinet Departments, The Department of Veterans 'Affairs manages one of the largest automated medical care systems in the nation through its Veterans Health Administration (VHA). VISTA (Veterans Health Administration Information Systems and Technology Architecture) provides the rich automated environment that supports day-to-day operations at VA health care facilities. This system incorporates VHA's previous information system — the Decentralized Hospital Computer Program — into a new, open system, client/server based environment including workstations with graphical user interface, software developed by VA employees, links to commercial-off-the-shelf software, and future incorporation of new technologies including Intranet and Internet. All VA facilities are electronically interconnected to centralized databases for administrative and clinical use. The interconnection allows data exchange throughout the entire VHA network.

STANDARDS EMPLOYED:

VHA has developed a portfolio of over 120 software applications written in the M (formerly MUMPS) American National Standards Institute (ANSI) standard programming language. The applications are based on a single data dictionary, which implements a standard set of data elements and data values.

VHA uses standard medical coding and classification systems, including: Physicians' Current Procedural Terminology (CPT); Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV); Health Care Financing Administration Current Procedural Coding System (HCPCS); International Classification of Diseases, Ninth Revision (ICD-9); International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM); Systematized Nomenclature of Human And Veterinary Medicine (SNOMED); and Logical Observations: Identifiers, Names, Codes (LOINC), and the ANSI ASC (Accredited Standards Committee) X12N Health Care Provider Taxonomy. VHA uses the Accredited Standards Committee (ASC) X12, Health Level Seven (HL7), the ISO/IEC (International Organization for Standardization/International Electrotechnical Commission) Standard 11179 Specification and Standardization of Data Elements, and the Digital Imaging and Communications in Medicine (DICOM) III standards for exchanging health care information between health care facilities and among applications.

VHA has developed a standard clinical lexicon for use in all applications. The clinical lexicon is based on the National Library of Medicine Unified Medical Language System (UMLS). VHA has also undertaken the creation of a Master Patient Index to uniquely identify and enumerate patients. The Master Patient Index maintains unique patient control numbers and a list of current facilities where the patient has been seen. VHA is considering implementing the national provider and payer identification systems that are being developed by the Health Care Financing Administration (HCFA).

PURPOSE OF STANDARDS:

The standards are implemented in VHA software applications and specified in applicable contracts for commercial products and services to ensure consistent representation of data and to facilitate the exchange of data between health care facilities.

SUBJECTAREAS COVERED:

The subject areas cover include virtually all aspects of health care and health status, such as electronic medical records; exchange of clinical information; ancillary tests and procedures; instrument interfaces; demographic, financial and eligibility information; scheduling information, privacy, data administration, confidentiality, and security.

STANDARDS ACTIVITIES:

VHA representatives participate in numerous informatics standards groups, including the American National Standards Institute (ANSI) Healthcare Informatics Standards Board, American Society for Testing and Materials (ASTM) Committee E3 1 on Healthcare Informatics, ASC X12N-Insurance Subcommittee, DICOM III, Institute of Electrical and Electronics Engineers (IEEE) and HL7. They attend meetings, propose improvements to existing standards, identify new standards that are needed, and review and comment on ballots of proposed standards. VHA also develops internal standards when external standards are not available or not applicable.

DATA DICTIONARIES:

The ANSI M programming language and the VA FileMan data dictionary provide an internal standard for representing data in VHA applications. VHA is also developing a corporate data registry based on the recommendations in ISO/IEC Standard 11179. VHA uses standard reference data sets, including CPT, DSM-IV, HCPCS, ICD-9-CM, LOINC, and SNOMED codes.

PUBLICATIONS AND OTHER DISSEMINATION:

Internal standards are disseminated through policy and other manuals. These manuals are distributed in both printed and electronic form; the latter though a VA Web page (http://www.va.gov), electronic mail, and the bulletin board. VHA has made arrangements with the HL7 Committee and the American Society for Testing and Materials to distribute their standards electronically throughout VHA. Other external standards activities are reported and distributed through electronic mail.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZA TIONS:

VHA representatives serve on international, national, and interagency standards organizations and committees, including: Global Information Infrastructure — G7 Global Healthcare Applications — International Harmonisation of Use of Data Cards in Healthcare Sub-project; HHS Data Council — Joint Working Group on Telemedicine, Interagency Health Privacy Working Group, and the Committee on Health Data Standards; ASTM Committee E3 1 on Healthcare Informatics; ANSI Healthcare Informatics Standards Board; IS0 TC2 15 on Health Informatics; ASC Xl 2N — Insurance Subcommittee; DICOM III; IEEE; and HL7. VHA representatives attend standards meetings, propose improvements to existing standards, identify new standards that are need, and review and comment on ballots of proposed standards. VHA also provides funds to support an HL7 Government Projects Special Interest Group to expedite processing of proposals that benefit the Government Computer-based Patient Record (GCPR) initiative.

HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA 1996) RELATED ACTIVITIES:

VHA is a member of the HHS Data Council — Committee on Health Data Standards and has representatives participating in various work groups that are addressing the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996.

- **Key Personnel Assigned to HIPAA Implementation:**

  Robert M. Kolodner, M.D.
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- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:**

  VHA is developing a process to standardize its health insurance claims and remittance processing activities through electronic data interchange using ANSI Xl 2 standards. VA will use value added network(s) to translate transactions to proprietary carrier formats, including paper UB-92s and HCFA-1500 where necessary, to accomplish a claim. All data transmitted between the VA and its value added network(s) will be formatted according to ANSI Xl2 standards. VHA will begin using TS 837, Health Care Claim and TS 997, Functional Acknowledgment. Transaction Segments planned for future implementation are: T.S. 277, Health Care Status; T.S. 835, Health Care Payment/Remittance Advice; TX 270, Health Care Eligibility/Benefit Information; and T.S. 276, Request for Status of Health Care Claim.

- **Plans or Planning Groups Established to Implement HIPAA Changes:**

  VHA plans to implement the recommendations of the National Committee on Vital and Health Statistics relating to the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996.

COMMENTS:

There is a need for a standard clinical terminology, especially in areas such as mental health.

Proposed legislation concerning privacy, confidentiality, and security will, if enacted, significantly affect VHA.

AGENCY: Consumer Product Safety Commission

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DATA-RELATED PROGRAMS:

CPSC is an independent Federal regulatory agency, charged with responsibility for reducing the risk of injury and death due to consumer products. In order to measure and track injuries and deaths related to consumer products, the Commission operates a number of data systems, among which are the following:

- ***The National Injury Surveillance System (NEISS),*** a hospital emergency department surveillance system designed to collect consumer product related injuries on an ongoing daily basis in a timely manner, is the Commission's primary data system. In 1997, 10 1 hospital emergency departments in the U.S. and its territories comprise a probability sample of all such hospital emergency departments. The Commission contracts with each participating hospital to provide surveillance data derived from emergency department records. Generally, these data are coded and entered into personal computers by hospital employees. A personal computer at CPSC headquarters collects the data nightly via another unattended personal computer. In addition to providing valuable surveillance data, the cases collected serve as a sampling frame for follow-back investigations of specific hazard types.
- ***The CPSC Death Certificate Project*** is designed to provide product data for a limited number of ICDA E Code categories purchased from the 50 states, the District of Columbia and New York City. Contracts are negotiated with each state to provide the in-scope death certificates in as timely a manner as is feasible. Those death certificates whose narrative provides sufficient detail are coded with CPSC's numeric product code and entered into a computer database. The number of death certificate categories purchased each year is subject to the available funds, and has varied over time.
- ***The Injury and Potential Injury Incident (IPII)*** file includes anecdotal data from many different sources: consumer complaints, newspaper clippings, medical examiner/coroner reports, fire departments, etc. These reports often serve to alert CPSC staff regarding hazardous or potentially hazardous consumer products.

STANDARDS EMPLOYED: NIA

PURPOSE OF STANDARDS: N/A

SUBJECTAREAS COVERED:

CPSC has jurisdiction over products customarily produced for sale to or use by consumers. Some excluded categories include motor vehicles, aircraft, firearms, pesticides and medical devices.

STANDARDS ACTIVITIES:

The Commission has the authority to mandate product standards, although standards may be developed voluntarily by industry groups.

DATA DICTIONARIES:

CPSC has developed its own data dictionaries and coding manuals specific to each database.

PUBLICATIONS AND OTHER DISSEMINATION:

The National Injury Information Clearinghouse serves as CPSC's information link to the public. Freedom of Information requests are handled by the Office of the Secretary. One available document is the *Consumer Product Safety Review*, published quarterly and available through the Superintendent of Documents.

PARTICIPATION IN ANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS: NIA

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELA TED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:** N/A
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:** N/A
- **Plans or Planning Groups Established to Implement HIPAA Changes:** N/A

COMMENTS: N/A

AGENCY: Office of Personnel Management

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DATA-RELATED PROGRAMS:

The Office of Personnel Management (OPM) is responsible for administering the Federal Employees Health Benefits Program (FEHBP) which covers approximately 9 million Federal employees, retirees, and family members. OPM has more than 350 carriers under contract servicing the FEHBP. The demand for current and accurate healthcare data is constant. In addition to contract administrative data, OPM is frequently requested to participate in major employer survey initiatives such as the annual Medical Expenditures Panel Survey (MEPS) and numerous other nationwide employer/health insurance studies.

STANDARDS EMPLOYED:

None mentioned.

PURPOSE OF STANDARDS:

N/A

SUBJECTAREAS COVERED:

N/A

STANDARDS ACTIVITIES:

None mentioned.

DA TA DICTIONARIES: NIA

PUBLICATIONS AND OTHER DISSEMINATION:

None mentioned.

PARTICIPATION IN ANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS: N/A

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELATED ACTIVITIES:

- **Key Personnel Assigned to HIPAA Implementation:** N/A
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:** N/A
- **Plans or Planning Groups Established to Implement HIPAA Changes:** N/A

COMMENTS: N/A

AGENCY: Social Security Administration

CONTACT:

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DATA-RELATED PROGRAMS:

Within the Social Security Administration (SSA), office A01.6 has responsibility for coordinating and demonstrating direct access to medical records for agency personnel who make medical determination for disability programs. The major initiative in this area is a partnership SSA is developing with the Department of Veterans Affairs (VA). Efforts are underway to establish a policy and operational framework which would permit State disability examiners online access to the automated patient records maintained by VA medical examiners. It is expected that this process will expedite the processing of veterans' for SSA disability benefits. The disability examiners work in State determination services (DDS) offices which make the medical and vocational determinations for SSA according to federal regulations.

The main goals of the partnership between SSA and the VA are to demonstrate that the direct access method is both legally and technically feasible and will improve customer service by reducing claims processing time. In addition, it is expected that the new system will reduce administrative costs for both the SSA and the VA.

The SSA's General Counsel has found legal support for SSA to obtain the medical records from the VA medical centers via the direct access approach. The general counsels of both organizations will begin to discuss the details of the policy and operational procedures needed to ensure compliance with the Privacy Act and other related requirements. Then, after resolution of other technical issues, pilot operations will proceed.

Upon successful completion of the pilot demonstrations the SSA will use this example as a model to encourage other medical institutions to allow SSA the direct automated access needed for more timely and efficient collection of medical evidence using electronic technology.

STANDARDS EMPLOYED:

None specified.

PURPOSE OF STANDARDS:

N/A.

SUBJECTAREAS COVERED:

N/A.

STANDARDS ACTIVITIES:

None specified.

DATA DICTIONARIES:

None specified

PUBLICATIONS AND OTHER DISSEMINATION:

None specified.

PARTICIPATION INANSI-ACCREDITED AND OTHER STANDARDS DEVELOPMENT ORGANIZATIONS: None specified.

HEALTH INSURANCE PORTABILITYAND ACCOUNTABILITYACT (HIPAA 1996) RELATED ACTIVITIES: None specified.

- **Key Personnel Assigned to HIPAA Implementation:** N/A
- **Reviews of HIPAA Related Transaction Standards Needs and Efforts:** N/A
- **Plans or Planning Groups Established to Implement HIPAA Changes:** N/A

COMMENTS: N/A